

## Rochester Celiac Support Group

Susan Kath called to order the regular meeting of the Rochester Celiac Support Group at 7:05 pm on March 18, 2009 at the Brighton Reformed Church, Rochester, NY

Topic: General Discussion

Meeting Chair: Susan Kath, President

Note Taker: Erin Collins, New Secretary

General discussion highlights:

- Congratulations to Cassandra Coffey for taking on the role of President of the RCSG effective July 1, 2009. Cassandra has done an outstanding job with the 2008 Annual Walk for Celiac Disease and is now working very hard on the 2009 Walk. She will be a strong leader for the group and has exhibited leadership, organizational and communication skills while chairing the walk the past two years and at the Advisory Board and regular monthly meetings.
- Erin Collins has answered our plea for a secretary and will start taking meeting notes and publish the highlights to the cellist.
- Elections will be held at our May meeting to Advisory Board positions. We need people for the following positions: Vice-President, Treasurer, Chairperson for the Annual International Walk for Celiac Research, and an At-Large Member. The RCSG is a wonderful and powerful force here in the Rochester area due to the dedication of many, many people over the years. Please contact any Advisory Board member or call Susan Kath at 585-425-9994 if you are interested.
- There is a new health food store in victor: Health & Harmony Natural Foods at 6385 State Route 96, Suite 200. They offer many gluten free dry goods and frozen products.

- We had gluten free cookbooks donated to the group by the New York State Council on Leadership and Student Activities. It is the student councils from the NY high schools. If you did not receive a cookbook, they will be available at future meetings to pick up (while supplies last).

- We need a volunteer to be the auctioneer for the Annual Gluten Free Auction Fundraiser on April 15th. No pre-work is required and we will provide some written instructions ahead of time. Just need to be enthusiastic and engaging the night of the auction. As a reminder, we do not collect dues and this event helps us raise money to cover our rent, supplies for meetings, and newcomer packages.

- Cassandra Coffey updated the group on the progress for the 2009 Celiac Walk which is on Saturday May 30th. Information about the Rochester Celiac Walk is available online and registration is open- sign up today at <http://www.celiacwalk.org/>. Also check out our walk website at <http://www.rochesterceliacs.org/walk09.htm> to see all of the great vendors and sponsors for this year's walk!

- There are a number of people working locally 'behind the scenes' promoting awareness of Celiac Disease on behalf of the RCSG and GIG. Some of these efforts are:

- o February 9 and March 10 Joel Elias did a presentation about CD for Preferred Care clients at its Wellness Center on Alexander Street.

- o February 28 and March 1 Joel Elias and Maureen Doyle met with Mario's Steakhouse kitchen and dining room staffs to present info on CD and food preparation.

- o Joel Elias and Susan Kath met with the manager at the Bushnell Basin location of the Great Northern Pizza Kitchen. GNPK is exploring the possibility of making GF pizza, chicken wings, soups and salads.

- o Our storyboards are currently at the Webster and Fairport libraries. In the past few months we have also had displays at the Downtown, Penfield, Pittsford and Henrietta libraries. Please contact me if you can arrange to have the storyboard in the library in your town.

- o Joel and Maureen met with the Gates Chili SD food service director and her staff for service training back in November 2008. They did a presentation about the science of CD and the proper preparation of GF foods.

- o Cassandra has been working with local TV channels to get a "Celiac Awareness" Public Service Announcement (PSA) on the air. Channels 8, 13, and 31 have received the tape and will be putting it into their schedule. The PSA is provided free of charge by the National Foundation for Celiac Awareness and features Heidi Collins of CNN speaking about CD.

o Marvin Becker has been working for over a year with food service management at both SUNY Brockport and the University of Rochester. Marvin has also been in contact with the owner of the Brazos Valley GIG List, which contains a listing by state of colleges with a gluten free menu and links to the schools. These resources are on our website at [www.rochesterceliacs.org](http://www.rochesterceliacs.org) under the heading GF at School in the column on the left.

#### Gluten Free Product Updates:

- Gluten Free Living and Living Without are both great magazines for people with Celiac Disease and gluten sensitivity.
  
- Green's Brewery produces a gluten free Belgian Ale. The founder, Derek Green, is a celiac. The beer is available at Wegmans.
  
- Conti sells GF stuffed pasta's that are available at Lori's Natural Foods.
  
- Mr. Ritts flour is great for substituting GF flour 1:1 for wheat flour in recipes.
  
- Some GF items are available only at Passover, so stock up now:
  - o Lieber's cake mixes- available at Price Right stores in the Passover section
  - o Ossem- GF pound cakes in the Passover section at Wegmans stores
  
- If you like Cerrone Cones and or anything else that you would like to see carried by your Wegmans store, call 1-800-WEGMANS, send a comment online, or ask the Nature's Marketplace manager at your store to carry it.

#### Upcoming Events:

- April 15th is our next membership meeting. It will be the Annual Gluten Free Auction Fundraiser. Bring gluten free goodies to the meeting to auction off to our members!
- May 3rd, our parent organization, GIG, is launching a new program, Chef to Plate Event on Sunday, May 3rd. It is a national awareness campaign for gluten free living, through the restaurants that support persons living with gluten intolerances. We are working to have one or two locations here in the Rochester area.
- May 20th is a membership meeting where we will hold nominations and elections for the board and discuss traveling on a gluten-free diet.
- May 30th is the 2009 Celiac Walk. Registration begins at 9:30am and the walk starts at 10:30am at Perinton Park. Click the link for more details.
- May 31st from 1 to 3pm, Lori's will be hosting a Gluten Free Tasting at the store in Henrietta.
- June 2nd, Wegmans will be hosting a GF tasting event at the Chili Conference Facility. More details to follow.
- June 5 and 6, 2009 in Seattle, WA is the GIG Annual Education conference. Dr. Peter H. R. Green will be the keynote speaker on Saturday night. Dr. Green is the Director of the Celiac Disease Center at Columbia University and the author of the book, "Celiac Disease A Hidden Epidemic". Go to [www.gluten.net/events.php](http://www.gluten.net/events.php) (scroll to conference info & register online) I sent an email about this on March 10th. If you aren't a member of GIG, sign up soon at [www.gluten.net](http://www.gluten.net).
- June 17th is a membership meeting where we will discuss the 2009 Celiac Walk and Kathy Oaks will be leading a gluten free cooking class about dealing with CD without spending a fortune; including topics such as cross contamination, social situations and eating at restaurants.

- July 15th is a membership meeting where we will discuss the GIG Conference and have an open discussion.
- August 7, 2009 (Friday) will be a new event for Celiac Awareness Day at Frontier Field. They have concessions with gluten free food at the stadium. We ask that our members wear their walk t-shirts.
- August 19th is a membership meeting where we will have a round-about discussion with parents and children to discuss the issues impaction celiac kids and their parents.
- August 23rd at 5pm at Biaggi's Restaurant, we will be having a fundraiser so please save the date. We would like you to come and bring family and friends.

Susan Kath adjourned the meeting at 8:45 pm.